TO: **ALL INTERESTED PARTIES**

FROM: **GRANTLAND JOHNSON**

DATE: **April 16, 2002**

SUBJECT **Long Term Care Council Status Report**

I am pleased to present to you the California Health and Human Services Agency's Report on the Long Term Care Council: Annual Progress Report as required by AB 452 (Mazzoni), Chapter 895 Statutes of 1999.

During the past year, the Council has focused on expanding home and community-based long term care (LTC) resources through the Governor's "Aging with Dignity" Initiative and funding; created a statewide Internet information resource directory to assist consumers, families, and local agencies find the resources available in their community; sought federal funding to support nursing home transition pilot projects; and reviewed and modified certain Medi-Cal waiver programs to take advantage of new federal rule changes and to assist more individuals with disabilities to live in the community.

AB 452 articulated a broad array of long term care issues for the Council to address. The Council is prioritizing its efforts and available resources in order to build a coordinated system of long term care in California. I hope this report will be helpful to the Legislature in its own strategic planning efforts.

N.B. Pages 12-17 of this report discuss federal grants that were not funded. On March 29, 2002, CMS notified the Departments of Health Services and Social Services that their grants, submitted last year, will be funded in the coming fiscal year. The departments will be reducing their grant's proposed budget and scope of work to reflect the federal funding amount received.

Enclosure

California Health and Human Services Agency

Long Term Care Council: Annual Progress Report

January 2002

Gray Davis
Governor
State of California

Grantland Johnson
Secretary
California Health and Human Services Agency

California Health and Human Services Agency
Long Term Care Council
Annual Progress Report 2002

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Section One--Overview

Introduction

The California Health and Human Services (CHHS) Agency Long Term Care (LTC) Council was established by AB 452 (Chapter 895 Statutes of 1999) (Government Code Section 12803.2). Annually, the CHHS Agency is required to report to the Legislature on its progress.

In August 2001, Governor Davis vetoed AB 1451 (Liu), which would have required the Agency to establish a LTC Financing Taskforce to evaluate the use of tax credits and deductions for LTC savings accounts as alternatives to LTC insurance. In vetoing the bill, the Governor directed the LTC Council (hereafter referred to as "the Council") to explore these alternative financing strategies in its 2002 Report to the Legislature. This analysis is contained in Section Four.

Council Structure

The LTC Council, as established in statute, is chaired by the Agency Secretary, and includes the Directors of the Departments of Aging, Developmental Services, Health Services, Mental Health, Rehabilitation, Social Services, Veterans Affairs and the Office of Statewide Health Planning and Development.

The Council was officially established in June 2000. Quarterly Council meetings have been occurring since that date. In January 2001, Secretary Johnson invited the Directors of the Department of Alcohol and Drug Programs, Housing and Community Development, and Transportation to also serve on the Council, given the importance of these services in supporting persons with LTC needs. A list of the expanded Council membership is presented in Appendix 1. The Council Meeting agendas are included in Appendix 2.

The legislation also established an Executive Subcommittee, chaired by a CHHS Agency Assistant Secretary, comprised of the appropriate deputies and other officers from the departments participating on the Council. This subcommittee is required to meet as frequently as necessary to conduct the Council's work. During 2000 and most of 2001, the Executive Subcommittee met on a weekly basis. In Fall 2001, the Subcommittee began meeting twice a month, unless additional meeting time was required.

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Goals

The LTC Council's duties, as articulated in AB 452, include:

- Promoting coordinated LTC planning and policy development, including the development of service and utilization data necessary for policy development;
- Developing as a first priority, strategies to improve the quality and accessibility of consumer information on the LTC programs administered by these state departments;
- Designing strategies to better monitor the consumer responsiveness of LTC services and programs;
- Developing strategies to streamline the regulatory process for LTC programs and services;
- Identifying subgroups needing LTC services who are under-served and developing strategies responding to their needs;
- Establishing priorities and timelines for carrying out the Council's duties;
- Reviewing and making recommendations on all LTC budget changes being proposed by departments participating on the Council; and
- Reporting annually to the Legislature on the Council's progress to date, commencing in January 2001.

The Council also has a central role in responding to the *Olmstead* decision at the state level. Appendix 3 provides a brief description of the *Olmstead* Supreme Court ruling.

Section Two--Key Activities

Public Forums

Overview

To gain input from LTC stakeholders, particularly consumers, families, and other concerned parties unable to travel to Sacramento to attend the Council meetings, the Council conducted four Public Forums in 2000-2001. The Agency planned and conducted these sessions, often with the assistance of a local sponsoring organization. The Agency Assistant Secretary assigned to the Council and several Executive Subcommittee members conducted these forums. Over 290 individuals attended these forums.

DATE	LOCATION	ATTENDANCE
November 28, 2000	Nevada City	45 individuals testified/ approximately 80 attended.
December 13, 2000	San Diego	42 individuals testified/approx. 84 attended.
January 11, 2001	Oakland	28 individuals testified/65 attended
February 21, 2001	Los Angeles	22 individuals testified/61 attended

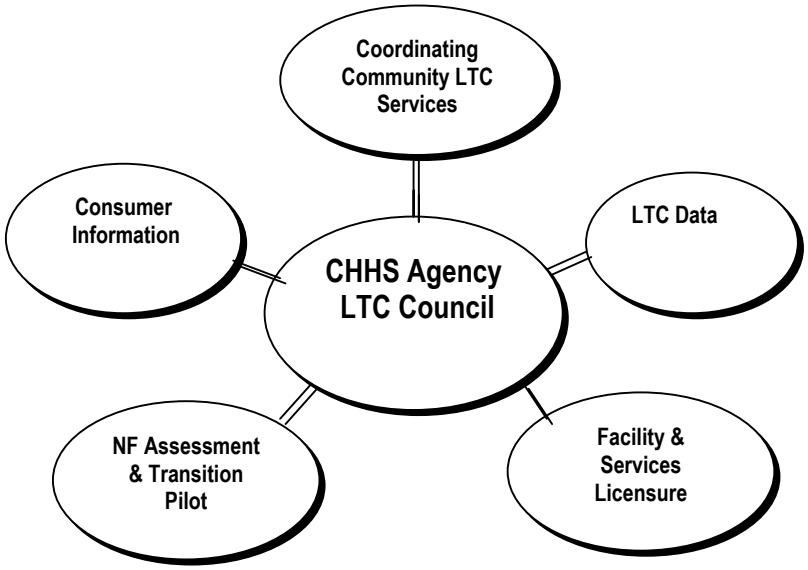
While there was some rural-urban variation in the comments received at these forums, some clear themes emerged. These included the need for family caregiver support; responsive consumer LTC information to assist in decision making; clarification on eligibility issues; outreach and service delivery responsive to the state's ethnic and cultural diversity; better assessment strategies for persons with cognitive limitations; and affordable, accessible housing; transport-ation; respite and mental health services. The difficulty in finding staff to provide LTC, from in-home, private pay workers to staff in residential and nursing facilities was repeated at all of the meetings. At several of the meetings, innovative service providers also came to speak about their programs. Appendix 4 presents a more detailed summary of the Public Forum comments.

Several of the forums "themes" became the basis for a federal grant application discussed in the Grant Application Section.

Council Workgroups

Overview

During Winter 2000, the Council established five workgroups, responsive to the Council's key goals. Each workgroup included not only interdepartmental staff but a broader group of stakeholders, ranging from LTC providers to consumer and advocacy group members as well.



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Council Workgroups, Continued

Coordinating Community LTC Services

This workgroup was established to improve interagency coordination among the key home and community-based long-term care programs. During 2001, the focus was on the In-Home Supportive Services, Adult Protective Services, Multipurpose Senior Services, Linkages, and Older Americans Act-funded care management services.

The **Departments of Aging and Social Services** co-chaired this large workgroup, which included many county and local representatives from the programs under discussion and other interested parties.

The workgroup has identified areas where coordination could be improved; obstacles that must be overcome for that to occur; and recommended next steps. These recommendations will be presented at the January 2002 Council meeting.

LTC Data

As a first step in maximizing the usefulness of the data currently being collected by public programs at the state level, this workgroup designed and completed an on-line inventory of that data.

The **Office of Statewide Health Planning and Development** chaired this workgroup, which included representatives from the departments represented on the Council and other interested parties. With the inventory nearly completed, the workgroup will now focus on:

- Developing the documentation needed so that the public can easily understand what is contained in this data inventory;
- Negotiate its on-going maintenance; and
- Identify ways in which this data can be used either independently or by being linked with other public LTC data to promote more informed LTC policy development.

Some of this workgroup's discussions and activities in 2002 will likely complement those of the University of California researchers involved in the implementation of SB 910 (See Section Three).

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Council Workgroups, Continued

Consumer LTC Information

This workgroup is focused on improving consumer LTC information both in terms of the usefulness of the content and its accessibility. During 2001, this workgroup:

- identified resource information currently available;
- analyzed key barriers to consumers understanding what LTC options are available to them;
- became familiar with emerging consumer information channels (e.g. the telephone "211" system being developed; internet self assessment tools, etc.); and
- beta tested Internet consumer LTC applications being developed at the national level (e.g., the "Benefits CheckUp" program) and at the state level through the "Aging with Dignity" Innovation grants.

The workgroup also recommended changes and enhancements to the state's *www.calcarenetwork.ca.gov* web portal, which have been made.

Among its 2002 activities, the workgroup plans to develop and share consumer-oriented information on Medi-Cal LTC services and the application process since none of the existing or newly developed web sites include any information on that topic.

The **Department of Rehabilitation** chaired this workgroup, which included representatives from state departments, consumer and advocacy groups, as well as family members and consumers of LTC services.

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Council Workgroups, Continued

Nursing Home Transition

This workgroup was established to:

- Create an assessment tool to assist in identifying nursing facility residents clinically appropriate for and interested in transitioning to a community setting; and
- Develop and implement a pilot program to facilitate this transition process.

During 2001, this workgroup first examined the current nursing home pre-admission screening assessment process (PASAR); reviewed and provided input on a draft DHS-developed nursing home transition assessment tool; and provided considerable input on the development of the NF Assessment and Transition Grant Application DHS submitted to the Center for Medicare and Medicaid Services (CMS, previously known as the Health Care Financing Agency). (More details follow in the next section).

The **Department of Health Services** (DHS) chaired this workgroup, which included representatives from state departments, a broad group of consumer and advocacy groups, as well as family members and consumers of LTC services. Implementation of this workgroup's planned activities clearly required additional resources, which was sought through the state budget process and the CMS grant application. As discussed in the next two sections, funding was not obtained from either source. However, this activity remains a high priority of the Council and it continues to seek funding to support this effort. This workgroup will be reactivated when the necessary funding is secured to implement this pilot program.

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Council Workgroups, Continued

Facilities and Services Licensure

This workgroup has examined the existing licensure requirements for in-home, residential, intermediate, and skilled nursing facilities to develop recommendations that can increase quality assurance; promote consistent public policy; encourage new models that provide care in more integrated settings; and provide licensure flexibility for services to evolve as local needs change.

The **DHS Licensing and Certification Program and the DSS Community Care Licensing Program** have co-chaired this large workgroup, which included various provider associations as well as consumer and advocacy organizations and other interested parties. The group met four times during the year, with intervening e-mail communications to identify recommendations and prioritize the potentially long list of recommendations.

Assisted Living Waiver

In Summer 2001, a workgroup was established to assist in the development of a Medi-Cal Assisted Living Wavier, as required by AB 499 (Chapter 557 Statutes of 2000). **The DHS Medical Care Services Program** has chaired this effort. Initial meetings provided an overview of the legislation; available models that could be built upon; and basic design issues that must be resolved for a waiver submission. These meetings have included provider associations, home and community-based agencies, and consumer and advocacy organizations. At this point, DHS is analyzing the basic fiscal components to the waiver before embarking on the more detailed wavier development activities.

Next Steps

During the past year, several Council workgroups were involved in processes aimed at priority setting and/or recommendation development. Recommendations from most, if not all, of the workgroups will be submitted to the Council at the January 31, 2002 meeting for approval.

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Council Workgroups, Continued

Next Steps (cont.)

During the coming year, several of the Council's workgroups will now focus on implementing their key recommendations. As previously noted, resources to implement the NF Assessment and Transition project will continue to be sought.

Recently passed legislative will also shape the Council's priorities and activities (See Section Three—Upcoming 2002 Activities).

Budget Proposals

Summary

The Departments participating on the LTC Council developed a number of budget proposals for potential inclusion in the Governor's 2001-2002 budget. Three specific Council proposals, that focused on testing new strategies for providing care in more independent, integrated settings, were included in the Governor's proposed budget. These included:

- Nursing Home Assessment and Transition Pilot Project--$500,000 in state general funds to develop an assessment tool and conduct a three-year pilot project to identify nursing home residents, desirous of and appropriate for transition into a more independent living arrangement, and to assist those residents in that transition.
- Institutions for Mental Disease (IMD) Pilot Project--$1 million in state general funds for three years to identify IMD residents who desire to and are appropriate for transition into a more independent community treatment setting and to assist them in that transition.
- Assisted Living Medi-Cal Waiver Development--$508,000 in state general funds to develop a Medi-Cal assisted living waiver as specified in AB 499, which would create another care option for individuals not able to live alone but not requiring 24-hour a day skilled nursing care.

Two of the three budget items were funded and are being implemented. Unfortunately, as a result of the budget shortfall, many budget items originally included in the budget ultimately could not be funded. The NF Assessment and Transition Pilot Project was among those items deleted from the final 2001-2002 budget.

Grant Applications

Overview

In a January 2001, CMS announced a major, $70 million multi-grant "Real Choice Systems Change" initiative seeking to expand the availability and quality of home and community-based assistance options for persons with LTC needs. Although announced in January, the actual Request for Proposals was not available until May 17, 2001 with grant applications due July 20, 2001.

Although states could potentially apply for three different grants (e.g., "Nursing Facility Transition," "Real Choice," and/or a "Community Based Attendant Services with Individual Control"), the likelihood of any state being awarded all three was remote. Strategically, the Council's Executive Subcommittee recommended applying for the largest grant opportunity (i.e., "Real Choice") and the NF Transition Grant.

In the category of grants available to independent living centers, the Santa Rosa Independent Living Center submitted a grant application with the full support of the DHS, as the single state Medicaid agency, and Agency's LTC Council.

Starter Grant

Because consumer involvement was identified as a significant element in the grant evaluation criteria, CMS offered states a one-time $50,000 "Starter Grant" to help them involve consumers and advocacy group stakeholders in the development of their Real Choice Systems Change grant applications.

The California Department of Social Services (DSS), on behalf of the LTC Council, was among the first state entities in the country to submit a Starter Grant application. The DSS had agreed to handle the payment of travel related expenses for consumers and grassroots advocacy group representatives participating in any of the grant development activities. However, even with DSS' speedy application, the formal CMS Starter grant notification was not received until early May. This left very little time to use the Starter Grant funding to solicit consumer and grass-roots advocacy group participation since the state Real Choice grant applications were due to CMS in just over a month's time.

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Grant Applications, Continued

Nursing Facility Transition Grant

The DHS, in partnership with the University of California, San Francisco, submitted a $1.2 million three-year grant application focused on a Nursing Facility (NF) Assessment and Transition Pilot Program.

The pilot proposed to establish a core group of care managers in six counties, who would identify NF residents clinically appropriate for and wanting to transition to a more independent living environment. The goal was to test whether an intensive level of care management and some flexible funding to assist in the transition would make it possible for additional NF residents to return to a more independent setting. The pilot sought to identify:

- The percentage of NF residents appropriate for and interested in transition and how best to identify these individuals;
- An appropriate assessment tool and process;
- Characteristics of residents who were (and were not) able to successfully make the transition and what the barriers to transition were;
- The number and characteristics of residents who were able to remain in the community after the transition;
- Service expenditures for residents transitioned to the community in comparison to NF residents; and
- The need for flexible funding to pay for transition expenses that cannot be paid for through Medicaid.

The LTC Council's NF Assessment and Transition Workgroup provided stakeholder input from departments on the Council as well as a broad range of provider, legislative, consumer and advocacy organizations in the grant development. The grant was submitted with 23 letters of support from these and other entities throughout the state.

As noted earlier, CMS did not fund DHS' grant proposal. DHS and Agency staff did participate in a follow up conference call with CMS to discuss the application's scoring. Reviewing the reviewers' scoring and comments provided some useful insights and guidance should DHS seek CMS funding for this project in the future.

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Grant Applications, Continued

Real Choice Systems Change Grant

The DSS submitted a $3.5 million three-year grant application focused on statewide enhancement to the existing In-Home Supportive Services (IHSS) Program. While the IHSS program is the largest consumer-directed personal care program in the country and the backbone of California's home and community-based LTC options, it historically has not provided support to its clients in managing their care. Recent legislative changes now require that counties must have an employer of record by January 2003 for purposes of worker collective bargaining; establishing a worker registry; and making consumer and worker training available.

The grant proposal sought to utilize this one-time funding to create consumer and worker training materials and opportunities statewide to assist the counties in meeting not only the employer of record but also the other important legislative mandates in a timely manner. By using these funds collaboratively, IHSS clients and workers throughout the state would benefit from resources that no one county could afford to develop or produce independently. Specifically the grant had four major objectives:

- Develop training, educational materials, and other strategies to assist IHSS consumers in understanding the program and self-directing their care;
- Identify training and other support needs of IHSS providers (almost half of whom are family members) and develop materials, tools, and other strategies to enable providers to improve the quality of the care they provide;
- Develop training tools and other materials to assist IHSS social workers to improve their skills in conducting IHSS needs assessments, particularly for disabled children and persons with cognitive and/or psychiatric disabilities; and
- Assist county eligibility workers to properly assess eligibility for disability-related programs.

These grant priorities were directly drawn from repeated comments made at the LTC Council Public Forums. The intent was to develop priorities for enacting these goals by conducting focus groups with consumers, providers, and county social workers and eligibility staff.

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Grant Applications, Continued

Real Choice Systems Change Grant (cont.)

The DSS convened a Real Choice Taskforce to provide input in the grant's development. Invitations were sent to over 55 individuals or organizations identified by the State Council on Independent Living as representing a very broad range of disability groups. Invitees include consumers of long term care services; representatives of grassroots/consumer advocacy organizations; provider associations; key legislative stakeholders; the County Welfare Director Association; and Public Authority representatives.

Two Taskforce meetings were scheduled to provide input on the proposed grant concepts and to refine the draft proposal. The grant was submitted with 27 letters of support from these and other entities throughout the state.

Unfortunately, CMS did not fund DSS' grant proposal either. A follow-up CMS conference call with DSS and Agency staff on the grant's scoring also provided valuable insights into the grant reviewers' thought process and understanding of the costs and complexities involved in implementing this type of grant in a state the size of California. These insights will be utilized if future federal grants are sought.

Independent Living Center (ILC) Grant

A component of the CMS Nursing Facility Transition Grant Program was potential funding (maximum of $600,000 over 36 months) available specifically to Independent Living Centers (ILCs) to enhance the assistance they currently provide to NF residents seeking to transition to a more independent setting. This was a very competitive grant category since only 6-8 ILC applications were to be funded.

Early on, Council Executive Subcommittee members met with the representatives from the State Independent Living Council (SILC), and the California Foundation for Independent Living Centers (CFIL), and core ILC representatives to encourage an ILC application and to coordinate California's Real Choice Systems Change grant development efforts. This level of coordination and inclusion between Department of Rehabilitation, the ILCs, and DHS Medical Care Services was noted as being "unprecedented" and was very positively received.

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Grant Applications, Continued

ILC Grant (cont.)

Community Resources for Independence, the ILC serving the Santa Rosa-Napa and North Coast area, submitted a Nursing Facility Transition Grant to provide technical assistance to the California ILC network on transition "best practices" and to support more intensive transition efforts in their catchment area. DHS, as the single state Medicaid agency, submitted a letter of support to accompany their grant application.

Unfortunately, CMS did not fund this grant application either.

Family Caregiver Grant

During this same time period, the Administration on Aging released a grant application in conjunction with the new federal Family Caregiver Support Program. The Contra Costa County Area Agency on Aging approached the CDA and the Council to discuss their concept and seek the state's endorsement for the proposal. Both CDA and Agency provided input and letters of support.

Contra Costa was awarded a $204,000 grant to be utilized over a three year time period, to test the efficacy of providing an independent care manager to assist the family caregivers of persons recently placed in a nursing home in:

- Learning how to most effectively advocate on behalf of that individual while they are in the facility; and
- Assessing whether available family and home and community-based services would make it possible for this individual to return home. If so, the care manger would help coordinate that transition.

Over the past decade, NFs have increasingly become a post-acute, rehabilitation stage following a hospitalization. This pilot will test the efficacy of focusing on family caregivers as a strategy to assist more NF residents in returning to their home. It will also measure whether peer training of family members on successful advocacy techniques will achieve improved quality of care and respect for the resident's rights and preferences.

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Grant Applications, Continued

Family Caregiver Grant, cont.	Contra Costa County has been an active and constructive participant on several of the Long Term Care Council's workgroups including the Nursing Home Transition Workgroup. The Council was very pleased that Contra Costa received this funding and will seek to assist the county in its implementation efforts.

Medi-Cal Waivers

Background

State Medicaid programs must include a basic package of benefits, including NF care for persons age 21 and over and home health care for individuals who would otherwise be eligible for nursing home care. States may then choose to provide up to 34 optional Medicaid services. California offers 32 of these services, such as expanded home health care, personal care services (e.g., the In-Home Supportive Services Program, etc.) intermediate care facilities for persons with developmental disabilities, adult day health care, medical transportation, rehabilitation, and physical therapy. (Wisconsin, the only state to surpass California, offers 33 of these optional services.)

Services provided under the Medicaid State Plan must be available statewide to any Medi-Cal beneficiary eligible for these services. States can also offer other services to more targeted Medicaid populations with special needs through federally funded waivers of the Medicaid statutes and regulations. However, Medicaid waivers cannot include the same services included in the state's Medicaid plan and the waivers must meet Medicaid budget neutrality requirements.

California currently has six home and community-based Medi-Cal waiver programs. During 2001, state departments represented on the Council have:

- Reviewed waiver waiting lists to ensure that sufficient "slots" were available for appropriate individuals to be enrolled in to these programs within a reasonable amount of time; and
- Where waiting lists existed, taken steps to expand the number of waiver slots.

It should be noted that waiting lists had developed for two waivers because fiscal issues with the waiver's structure required resolution before CMS would approve waiver expansions. Medi-Cal waivers to be amended, expanded and/or redesigned are discussed further in this section.

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Medi-Cal Waivers, Continued

MSSP Waiver

The Multipurpose Senior Services Program (MSSP), a Medi-Cal home and community-based waiver program, is a service option for persons age 65 and over who are certified at a nursing home level of care, but can remain in the community with care management and additional in-home and/or community LTC services.

MSSP began with 8 sites and 1,900 clients. While it has grown incrementally over the years, in 1998-99, the program grew considerably, expanding to 35 sites and 9,300 client slots that year. In 2000-02, the program grew to 41 sites and 11,789 client slots.

In 2001, CMS revised its rules, permitting Medicaid payment for care management costs incurred in assisting NF residents to transition into the community. In response to this new opportunity, CDA began researching and identifying the administrative and systems changes required to include these new features in the MSSP waiver. The necessary wavier amendment will be developed and submitted in 2002. With CMS approval, these changes will make it possible for MSSP sites throughout the state to begin assisting NF residents in their discharge planning with the goal of helping them move out of the facility and into the community.

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Medi-Cal Waivers, Continued

NF & Model Waivers

The NF and the Model Waivers are Medi-Cal home and community-based programs for persons who would otherwise need nursing facility care for 90 days or longer. The major difference between the two waivers is the financial eligibility component. The Model waiver allows for the use of "institutional deeming" to confer Medi-Cal eligibility. This means that for minor children or married individuals, parental or spousal income does not need to be taken into consideration for financial determinations and the person is evaluated "as if" he or she were in an institutional setting. Historically, the Model NF waiver has primarily served persons under age 18, who needed these special deeming rules.

In 2001, several states received considerable praise from disability advocates for Governor's Executive Orders or legislation aimed at enacting programs so that "the funding followed the person when they left the nursing home." The NF and Model waiver were created to provide exactly that type of support in California since they were implemented in 1996.

Medicaid waivers must be budget neutral. In other words, waiver expenditures can be for no more than the equivalent amount that would have been expended for a similar population in a California NF. The waiver services primarily provided case management, skilled nursing care, home health aide, and utility coverage. The NF and Model waivers were originally authorized to serve 472 and 110 individuals respectively. After implementation, the number of persons to be served under the waiver would increase. Currently, the maximum number is 546 and 245, respectively. Over the last two years, these waivers have begun to develop waiting lists. However, DHS could not immediately seek expansion of the waivers because of federal and state concerns over the waivers' cost neutrality.

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NF & Model Waivers (cont.)

In December 2001, DHS formally submitted two waiver applications for CMS review. The current NF Waiver will be revised to include two level of care categories: NF A, reflecting the need for continuous nursing care, and NF B, reflecting the need for intermediate nursing care. A new Subacute waiver will be submitted to serve individuals who meet the criteria for care in a subacute facility. The revised NF and the new Subacute waivers will include the same set of services and both will include "institutional deeming." The only difference will be the level of care required.

If approved as submitted, individuals currently served by the NF or Model NF waiver will be reassessed and transitioned (if necessary) into the NF or Subacute waiver, based on their identified level of care needed. The waivers have been redesigned to maximize the choices available to the waiver participants. While the previous waivers utilized nursing care services extensively, the revised waivers will offer the client a menu of services that will also include less medically oriented supportive services. These services will include personal care, defined as hands-on care and/or companion services, and respite. Both services may be provided by unlicensed caregivers. By adding more flexible supportive services and by introducing a per client "budget" (rather than an aggregate waiver "budget"), clients will be able to maximize the funds available and DHS will be able to assure the waivers' budget neutrality.

DHS anticipates that CMS approval of these redesigned waivers between April and July 2002. Once fully operational, DHS anticipates that existing waiting lists will be significantly reduced or eliminated. Based on anticipated performance, an annual increase in the number of waiver slots has been included in the redesigned submissions.

The re-design of these waivers should considerably expand consumer choice, offer consumers more cost-effective and desired options, and allow significant incremental expansion of these waivers.

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Medi-Cal Waivers, Continued

AIDS Waiver

The AIDS waiver serves Medi-Cal recipients with mid-to-late stage HIV/AIDS who, without these services, would require nursing facility or hospital care. To demonstrate cost neutrality, DHS must collect expenditure data on a comparable group of beneficiaries who are not in the waiver and provide that report to CMS annually. Simply put, spending for the waiver population cannot exceed that which is spend for the comparison group of Medi-Cal recipients.

DHS has modified the comparison group's composition to ensure that its characteristics are very similar to those in the AIDS Waiver, particularly in terms of their level of disability and need for ancillary services, including AIDS/immunodeficiency drug therapies. They have also made adjustments so that the same time period is used to track expenditures for both the waiver and comparison population. DHS anticipates that CMS will approve these changes on or before April 1, 2002.

Other Key Activities

Coordination of Various Special Projects & Groups

Over the past several years, a number of initiatives, grants, and pilot programs have been established to address a variety of LTC issues. By their nature, most of these are multi-departmental projects. On a regular basis, the LTC Council requests updates from these programs and initiatives. If warranted, the Council becomes more closely involved in these efforts to resolve cross-departmental issues that may develop or to provide the multi-departmental resources required to advance these projects.

This approach encourages program administration at the appropriate departmental level but musters needed additional resources when the need arises. These special projects, initiatives, and groups include, but are not limited to, the following:

- Innovation Grants—A component of Governor Davis' "Aging with Dignity" Initiative, these 28 seed grants, totaling $14 million, are creating new home and community-based LTC resources and alternatives throughout the state (a separate report to the Legislature will provide an update on these grants);

- Supportive Housing Initiative Act (SHIA) Project—Administered by Department of Mental Health in collaboration with the Department of Housing and Community Development, this program provides supportive housing grants to develop affordable, permanent housing with supportive services to enable low income Californians with disabilities to stabilize their lives and regain a stake in the community;

- Caregiver Training Initiative—Administered by the Employment Development Department, this $25 million grant program seeks to recruit, train, and retain LTC staff to provide direct care in home, residential, and skilled nursing facility settings; and

- Alzheimer's Disease and Related Disorders Advisory Committee—This advisory group provides input to the Agency on a broad range of issues pertaining to persons with dementia and their caregivers.

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Other Key Activities, Continued

Correcting Data Inaccuracies

Recently two reports have been released that presented inaccurate or misleading information on California's Medi-Cal LTC spending. In late 2001, CMS released the annual analysis of Medicaid LTC spending, prepared by MEDSTAT, a health information company. After its release, MEDSTAT received inquiries questioning the California waiver expenditure information. MEDSTAT believes it has identified the source of the discrepancy and prepared a revised table to provide more accurate California and New York data. MEDSTAT sent a memo to CMS and the appropriate state entities articulating the issue and sharing its revised expenditure table. Agency and DHS are reviewing this revised information to determine whether it reflects the state's actually Medi-Cal waiver spending.

But beyond this issue, the report is inaccurate, in that it only reports on waiver expenditures and does not include other Medicaid expenditures paid for through state plan services and state general fund only expenditures. Most states rely only on Medicaid waivers to provide most of their home and community-based LTC services. So, for those states, this report is an accurate reflection of their expenditures. However, in California, Medi-Cal LTC services are provided both in the state plan and through waivers. IHSS expenditures reimbursed by Medi-Cal (over $2 billion in 2000) are not reflected in this report because they are state plan rather than waiver services.

Unaware of the report's limitations, it is frequently cited at the federal level. For example, Government Accounting Office (GAO) testimony to the U.S. Senate Special Committee on Aging on September 24, 2001, based on the MEDSTAT report, portrayed California as being among the states spending less than 20% of its Medicaid funds on home and community-based LTC. In fact, virtually half of all Medi-Cal LTC expenditures were for non-institutional care and services in 2000.

The Agency and DHS are continuing to analyze the MEDSTAT report findings and will be working with MEDSTAT to insure that California home and community-based LTC expenditures are fully represented in future reports. In the meantime, Agency will provide the correct expenditure information to the GAO and the Senate Special Committee. This information will also be sent to the appropriate California Assembly and Senate members and committees.

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Other Key Activities, Continued

Summary

During 2001, the Council's numerous activities reflected four key objectives:

- Expanding home and community-based LTC resources;
- Creating new on-line information resources to help consumers, families, and local agencies find the full range of care options available in their community;
- Seeking resources to fund pilot projects focused on assisting individuals to transition to more independent setting; and
- Making the necessary Medi-Cal waiver changes to permit these existing programs to expand and/or provide additional services that had not previously been included.

Numerous stakeholders who participated on the Council's workgroups and/or attended Council meetings have seen and commented on the Council's unprecedented interdepartmental collaboration on current projects and planned future activities. To the extent that this has been achieved, one of the fundamental legislative goals in establishing the Council has been accomplished.

However, successful coordination occurs only in the present tense and must be vigilantly maintained. Hopefully, the current level of interdepartmental coordination will continue to expand further and deeper down into the departments' programs in the coming year through the Council's workgroups and other activities.

The Council has also established crucial working relationships with a broad range of LTC stakeholders, including consumer and advocacy groups, providers, and county and local agencies. During the coming year, the Council will continue to seek opportunities for LTC consumers, their families and their caregivers to participate in these various activities.

Section Three--Upcoming 2002 Activities

Overview

In addition to the Council's workgroup activities discussed in Section 2, during 2002 the Council will also have a lead or coordinating role in the following:

- SB 639 Taskforce Under the auspices of the Council, Agency will convene a taskforce to identify barriers to mental health treatment for persons with Alzheimer's Disease and related dementias and make recommendations to improve their access to treatment. Addressing this issue is important since it represents a sizeable portion of the LTC population who will become nursing or psychiatric facility residents unless alternative options are developed;

- Strategic Plan on Aging Under the auspices of the Council, Agency will continue to collaborate with the University of California researchers and other stakeholders, in developing a strategic plan to address the impending demographic, economic, and social changes that will occur as a result of the rapid growth and diversification of California's aging population as required by SB 910 (Chapter 948 Statutes of 1999);

- Medi-Cal Assisted Living Pilot Project The Council will continue to provide technical assistance to DHS in the development of this waiver required by AB 499 (Chapter 557 Statutes of 2000); and

- Medicaid Infrastructure Grant The Council will provide technical assistance to DHS in implementing this federal grant effective January 2002. The grant will be used to create the "California Health Incentive Improvement Program," focused on expanding enrollment in the 250 Percent Working Disabled Program (e.g., persons with disabilities who are within 250% of the federal poverty level seeking competitive employment) and examining the feasibility of extending personal care services to the workplace.

Continued on next page

Upcoming 2002 Activities, Continued

Comments

The current economic downturn will force hard decisions during the state's 2002-2003 budget negotiation process. While the Council will undertake the above mentioned responsibilities within its existing resources, its actions will continue to be directed by its mission, vision, and guiding principles (included in Appendix 5) and three over-arching goals:

- Preserving the existing LTC infrastructure even during this difficult economic period, while continuing to focus on incremental expansion of home and community-based care options;
- Creating and disseminating LTC information that will inform consumers about the full range of care options available to them; and
- Continuing to develop responsive oversight mechanisms to ensure the quality of the LTC provided whether it is in an in-home, community, residential or skilled facility setting.

Web Resources

Updated Council information, including notices of upcoming meeting dates and locations and workgroup activities, can be found at www.chhs.ca.gov/longtermcare.

Section Four--Alternative Private LTC Financing Options

Overview

AB 1451

AB 1451 (Liu) would have required the Secretary of the Health and Human Services Agency to establish and chair a LTC Financing Taskforce to report to the Legislature on private alternatives to LTC insurance. Alternatives to be studied were to "include tax credits and deductions for a LTC savings account that is [sic] similar to an individual retirement account." The taskforce was also to develop recommendations "on how to improve Medi-Cal to serve the long-term care of Californians."

Governor Davis vetoed the bill, noting that the goals set forth in AB 1451 could "be fully realized by the existing Long-Term Care Council" and he instructed the Council to analyze in its 2002 Report to the Legislature on the potential of the private LTC financing alternatives noted in AB 1451. That information is contained in this Section.

In the mid-1980's, various private LTC financing options were under consideration, including individual LTC insurance policies; single premium annuities; combined life and long term care insurance policies; LTC IRAs; and pension benefit options[1] These options varied greatly in terms of design feasibility and marketability, but represented the range in thinking on the topic at that time. In the ensuing years, individual and group LTC insurance products have evolved further than the other options, which have remained in a conceptual state.

In preparing this report, Agency staff conducted a literature review, contacted the AARP Policy Institute, and other experts in the field of LTC financing to determine whether any new "alternative" LTC financing options are under serious consideration either by public policy organizations or financial investment or insurance industries. None were identified.

Continued on next page

[1] Susan L. Hughes, Long-Term Care: Options in an Expanding Market (Homewood: Dow Jones-Irwin, 1986), 237.

Summary (cont.)

Nevertheless, this analysis examines existing private LTC financing options; discusses the features and potential applicability of the options identified in AB 1451; and briefly reviews other existing non-insurance financing options. A table comparing the features of LTC insurance products, flexible spending accounts, medical service accounts, and Individual Retirement Accounts (IRAs) is provided. (See Table A—Potential Private LTC Financing Strategies).

Table A--Potential Private Long Term Care (LTC) Financing Strategies

	Long Term Care Insurance (LTCI)	Flexible Spending Account (FSA)	Medical Service Account/Medicare+Choice MSA) [1]	Individual Retirement Account (IRA)
Purpose	Provides reimbursement for a defined set of LTC expenses once the eligibility criteria is met.	Allows employees to set aside funds, on a pre-tax basis, to pay for qualified expenses. [2]	Designed to compliment small business health insurance plans with high deductibles and copayments. MSAs permit employees to set aside funds, on a pre-tax basis, to pay for qualified expenses.	Bank or brokerage account for tax-deferred retirement savings. Maximum 2001 annual contribution was $2,000.
What's Covered	Comprehensive policies usually cover in-home, community, residential, and nursing facility care. Other types of policies may restrict coverage to certain care settings.	Qualified expenses include medical costs not covered by the health plan including monthly premiums, deductibles, dental and vision expenses, etc.[3]	Qualified expenses include medical costs not covered by the health plan including monthly premiums, deductibles, dental and vision expenses, etc	Withdrawn funds can be used for any purpose.
Who Is Eligible	Adults under age 84, in reasonably good health, can purchase LTCI.	Employees of companies that offer FSA benefit.	Self-employed and employers/employees of companies with 50 or less workers. Individual must be covered by a qualified major medical insurance policy but not any other health insurance including Medicare.	Any person who receives taxable compensation during the year and is not age 70 ½ by the year's end.

Table A--Potential Private Long Term Care (LTC) Financing Strategies (cont.)

Tax Implications	LTCI premiums can be deducted if medical expenses are itemized and exceed 7.5% of adjusted gross income (AGI). LTCI benefits received are not taxable	FSAs allow employees to reduce their taxable income and use that reduced amount to pay for expenses that would otherwise be paid from after-tax income. Funds remaining in the FSA at the end of the benefit year revert to the employer.	Cash contributions during a tax year are deducted from reported federal gross income. Interest earnings accumulate on tax-deferred basis. MSA withdrawals for qualified expenses are exempt from federal income tax. After age 65, funds can be withdrawn for any reason, but taxes are due on withdrawn funds.	Withdrawal from an IRA account prior to age 59 ½ carries significant tax penalties. (See Limitations below.)
Advantages	Insurance risk pooling results in more affordable coverage than many consumers could individually afford. Provides full coverage whether policy is in force for 1 or 20 years.	FSA funds could be used to pay for LTCI premiums.	MSA funds can accumulate from year to year. MSA funds could be used to pay for LTCI premiums (or deductibles, co-payments, or expenses not covered by LTCI).	IRAs could be used as a tax-deferred savings mechanism for potential LTC expenses.
Limitations	LTCI is medically underwritten, thereby excluding people who currently have LTC needs or have health conditions likely to result in LTC needs in the near future. Like other types of insurance, if there is no claim, there is no return on premiums paid in.	Account funds not spent during benefit year are forfeited. So, while useful for LTCI premium payment, they are not a viable option for LTC savings on an on-going basis.	Only available to employees in small companies. Contributions not permitted after age 65. Substantial funds would need to be accrued prior to age 65 to provide sufficient funds to pay for several years of potential LTC need. Both are pilots due to expire on 12/02. [4]	IRAs cannot be used to pay for LTC expenses prior to age 59 ½ unless those expenses exceed 7.5% of the individual's AGI. Those over age 70 must take regular distributions even if they do not need the income and cannot continue to make IRA contributions.

1. CMS had not yet approved any high deductible health plans so MSAs are only "conceptual" options at this point.
2. FSAs are authorized in Internal Revenue Code(IRS), Section 125.
3. IRS Section 213(c) defines "Medical care."
4. More information on MSAs and Medicare+Choice are available from the CMS website www.medicare.gov.

Existing Options

LTC Insurance Options

LTC insurance has evolved significantly over the past 15 years, becoming the most well known private LTC financing mechanism. An estimated 5.8 million policies have been purchased in the United States through June 30, 1998. This represents a 5% market penetration rate, although penetration in California is about 7%.[2]

In 1991, DHS implemented the California Partnership for LTC, a public-private partnership to:

- Improve the standards for LTC insurance policies sold in the state;
- Create more affordable insurance options by linking the policy payment amount to assets that could be exempted if an individual later applied for Medi-Cal; and
- Educate Californians about the need to plan ahead for potential LTC needs. More information on the California Partnership for LTC, and the LTC insurance companies participating in this program, is available at www.dhs.ca.gov/cpltc.

Group LTC insurance products, primarily offered through employers, have also increased. In 1998, over 2,000 employers offered LTC insurance coverage, usually on an employee-pay-all basis. The California Public Employment Retirement System (CALPERS) LTC insurance program, a self-funded plan with a third party administrator, represents one of the largest group LTC insurance programs in the country. Federal workers will also soon be offered an employer sponsored (employee-pay-all) LTC insurance program.

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[2] Health Insurance Association of America, Long-Term Care Insurance in 1997-1998: Research Findings (Washington, D.C., 2000).

Existing Options, Continued

Tax Credits

In 1996, state legislative changes made it possible for Californians who purchased LTC insurance to deduct qualified LTC insurance premiums when filing their state income tax return.[3]

In 1997, the federal Health Insurance Portability and Accountability Act (HIPAA) defined premiums paid for tax qualified LTC insurance policies as medical expenses. However, individuals must itemize medical expenses on their federal tax return to utilize this deduction.

In 2000, as a component of Governor Davis' "Aging with Dignity" Initiative, a $500 tax credit was enacted permitting eligible caregivers to claim a state tax credit for LTC expenses paid on behalf of seniors or other adult family members.

In examining the usefulness of federal or state tax credits as a strategy to encourage Californians to plan ahead for potential LTC needs, it is important to remember that nearly half of the population over age 65 do not have taxable income that would require them to owe taxes.[4]

Continued on next page

[3] AB 64 (Alquist) would amend the existing LTC insurance tax deduction provisions authorizing an above-the line personal income tax deduction equal to a percentage of the LTC insurance premiums paid under certain conditions.

[4] AARP, Long-Term Care: The Public Policy Book: AARP Public Policies, 2000 (Washington, D.C. 2000), 7-62.

Potential Options

Flexible Spending Accounts

Flexible spending accounts permit employees to set aside income, on a pre-tax basis, for qualified expenses such as medical or dental expenses not covered by their health insurance. This type of account could be used to set aside the needed funds for annual LTC insurance premiums. However, this is not a viable option for building up funds that would grow with interest to pay for potential future LTC needs. Any funds not used by the individual during the benefit year are forfeited.

Medical Service Accounts

Medical Service Accounts (MSAs) are individual savings accounts designed to wrap around employer health insurance policies that have high deductible and co-payment amounts. Conceptually, these products would encourage small employers that could not afford comprehensive worker coverage to offer at least a basic health insurance policy. Workers could then place income into a MSA to pay for those deductibles and co-payments. MSA contributions are deducted from a worker's federal gross income. These accounts can be maintained from year to year and interest accrued is tax-deferred.

So, if an individual works for a small employer and meets the MSA eligibility requirements specified in Table 1, theoretically they could use this account to fund potential LTC needs. However, individuals working for small employers are likely to have health care or pharmacy expenses not covered by their health insurance and would likely need to rely on this type of account for acute or primary health care expenses rather than potential future LTC needs. Finally, it is important to note that CMS has not yet approved any high-deductible health plans, so MSAs are not actually available at this time.

Individual Retirement Accounts

Individual Retirement Accounts (IRAs) are well known tax-deferred retirement investment options available to anyone. The annual maximum amount that can be placed in an IRA account is based on an individual's adjusted gross income. The maximum amount for 2001 was $2,000.

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Potential Options, Continued

Individual Retirement Accounts (cont.)

However, as currently structured, an IRA has fundamental flaws as a LTC financing mechanism. If any individual sustained a disability before age 59 ½, they would incur substantial penalties for the early withdrawal of IRA funds. By age 70 ½, individuals must begin making IRA withdrawals annually or face serious tax penalties. Most individuals do not develop LTC needs by age 70, yet they must begin to tap into that resource by that point.

Living Benefits

Viatical agreements and accelerated death benefits, often referred to as "living benefits," can provide some assistance in paying LTC expenses. Some individual life insurance policies can be purchased that include a LTC benefit. Under an accelerated death benefit rider, the insurer pays a portion (usually 25-50 percent) of the life insurance benefit to the policyholder instead of paying the full amount to the beneficiary at the policyholder's death. Three conditions currently trigger this accelerated payment:

- Terminal illness resulting in less than 12 month life expectancy;
- Catastrophic disease (such as stroke); or
- Permanent confinement to a health facility, such as a nursing home.

Terminally ill persons can also sell their life insurance policy to a viatical settlement company for an immediate payout. These companies typically purchase a life insurance policy for 50-80 percent of the death benefit.[5]

These options have limitations as LTC funding sources. A life insurance policyholder may need LTC assistance but not meet the trigger for an accelerated payment or the living benefit may limit where the payment can be used (e.g., health facility only). Living benefit policy payments may make a person ineligible for some means-tested public programs.

Continued on next page

[5] Ibid., 7-67.

Other Available Private Financing Options

Reverse Mortgages

Reverse mortgages allow older persons, who own their own home, to convert their home equity into cash. Since most older Californians are homeowners without a mortgage and the value of that home is their largest asset, using a reverse mortgage to pay for needed LTC assistance conceptually seems appropriate. However, on-going in-home assistance is expensive and the amount available from the reverse mortgage may not be sufficient to pay for that care. Reverse mortgage loan fees are "front loaded" making them most appropriate for individuals who plan to stay in their home for a number of years. These loans usually become due when the home is sold, the individual dies or the individual is no longer living in the house. So if the individual is in an assisted living or nursing facility, which could trigger the loan's repayment.

Retirement Communities

Individuals can also sell their home and use those funds to purchase a housing unit in a Continuing Care Retirement Community (CCRC). Residents pay a large one-time entry fee plus a monthly maintenance fee in exchange for the assurance of lifetime LTC. CCRCs are licensed by the DSS Community Care Licensing Program.

Comments

Most private LTC financing approaches share two major limitations:

- Consumers must acknowledge their potential future need for LTC assistance and be willing to act on that potential need. Most individuals live in denial that they will ever need LTC assistance and most individuals still believe that Medicare covers LTC expenses. (Medicare does not cover custodial LTC assistance); and
- Consumers must have the disposable income necessary to pay the insurance premiums or to invest toward that potential future need.

Most of these options rely on building up savings for decades to generate a large enough investment to finance LTC needs for several years. LTC insurance policies may have a 3-6 month exclusion period after the initial purchase, but after that, if premiums continue to be paid, the individual is eligible for the full policy benefits.

Continued on next page

Overview, Continued

Comments (cont.)	State policymakers' interest in increasing private long term care financing alternatives, is commendable. However, engaging the financial services industry to develop new or modify existing products to be marketed in one or a limited number of states is not easily achieved. How these savings investments are treated by the Internal Revenue Services (IRS), which states have no control over, can significantly impede or encourage a product's success in the marketplace.

Appendix 1--CHHS Long Term Care Council Membership

Chairman

Grantland Johnson
Secretary, Health and Human Services Agency

Council Members

Cliff Allenby
Director, Developmental Services

Diana Bontá
Director, Health Services

Julie Bornstein
Director, Housing and Community Development

Dr. Catherine Campisi
Director, Rehabilitation

Kathryn Jett
Director, Alcohol and Drug Programs

Dr. Stephen Mayberg
Director, Mental Health

Jeff Morales,
Director, Transportation

Rita Saenz
Director, Social Services

Lynda Terry,
Director, Aging

Bruce Thiesen
Secretary, Veterans Affairs

Dr. David Carlisle
Director, Office of Statewide Health Planning and Development

Appendix 2--Council Meeting Agendas

January 24, 2001
April 18, 2001
July 19, 2001
October 17, 2001

You are invited to

The Long Term Care Council Meeting

Department of Consumer Affairs

400 R Street—First Floor Hearing Room, Sacramento, CA 95814

January 24, 2001 1:30 – 4:30

Agenda

1. Opening Comments—Grantland Johnson, Secretary, CA Health and Human Services (CHHS) Agency (10 minutes)

2. Updates: (30 minutes)

   --Overview of "New Directions for Elder and Dependent Adult Abuse and Adult Protective Services in California—A 6 Month Report"
   Rita Saenz and Donna Mandelstam, DSS

   --Implementation of the Supportive Housing Initiative Act (SHIA)
   —Dr. Stephen Mayberg (DMH))

   --"Aging with Dignity" Challenge Grants—Lynda Terry, Dept. of Aging

   --"Caregiver Training Initiative" Grant Awards—Agnes Lee, CHHS

3. "California Cares" Internet Site Demonstration—DSS, Community Care Licensing (15 minutes)

4. Report from the Executive Subcommittee

   -- ACTION ITEM: Adoption of the Draft Mission, Vision and Guiding Principles statements (15 minutes)

   - Executive Committee Presentation on the proposed changes
   - Council Action

   --Governor's Proposed Budget: Long Term Care Issues (15 minutes)

   --LTC Council Public Forums—Update and Key Themes (10 minutes)

   --LTC Council Work Groups—Updates (10 minutes)

5. General Public Testimony (60 minutes)

6. Closing Remarks (10 minutes)

Chairman

Grantland Johnson
Secretary, Health and Human Services Agency

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Diana Bontá
Director, Health Services

Dr. Catherine Campisi
Director, Rehabilitation

Dr. Stephen Mayberg
Director, Mental Health

Rita Saenz
Director, Social Services

Lynda Terry,
Director, Aging

Bruce Thiesen
Interim Secretary, Veterans Affairs

Dr. David Carlisle
Director, Office of Statewide Health Planning and Development

You are invited to

The Long Term Care Council Meeting

Department of Water Resources
1416 Ninth Street—First Floor Auditorium, Sacramento, CA 95814
April 18, 2001 1:30 – 4:30 p.m.

Chairman

Grantland Johnson
Secretary, Health and Human Services Agency

Council Members

Cliff Allenby
Director, Developmental Services

Diana Bontá
Director, Health Services

Julie Bornstein
Director, Housing and Community Development

Dr. Catherine Campisi
Director, Rehabilitation

Kathryn Jett
Director, Alcohol and Drug Programs

Dr. Stephen Mayberg
Director, Mental Health

Jeff Morales
Director, Transportation

Rita Saenz
Director, Social Services

Lynda Terry,
Director, Aging

Bruce Thiesen
Interim Secretary, Veterans Affairs

Dr. David Carlisle
Director, Office of Statewide Health Planning and Development

Agenda

1. Introductions and Opening Comments—Grantland Johnson, Secretary, CA Health and Human Services (CHHS) Agency (10 minutes)

2. Outreach to Hispanic and Asian Communities--Rosa M. Ramirez, Director of Education and Outreach, Los Angeles Alzheimer's Association (20 minutes)

3. Long Term Care Integration Pilot Program (AB 1040) Update (35 minutes)

   Carol Freels, Acting Chief, DHS Office of Long Term Care

4. Report from the Executive Subcommittee

   --LTC Council Work Groups—Updates (20 minutes)

   - Coordinating Community LTC Programs Workgroup
   - LTC Data Workgroup
   - LTC Information Workgroup
   - Licensing and Regulation Workgroup

   --LTC Council Public Forums—Key Themes (10 minutes)

   --Informal Comments on the Council's Activities (5 minutes)

7. General Public Testimony (60 minutes)

8. Closing Remarks (5 minutes)

You are invited to

The Long Term Care Council Meeting

Employment Development Department

722 Capitol Mall, Main Auditorium

July 19, 2001 1:30 – 4:30 p.m.

Agenda

1. Introductions and Opening Comments—Grantland Johnson, Secretary, CA Health and Human Services (CHHS) Agency (10 minutes)

2. Traumatic Brain Injury Centers (35 minutes)

   Holly Johnson, Chief, DMH Children and Adult Programs and Representatives from the TBI Centers

3. "Strategic Planning Framework for an Aging Population" (35 minutes)

   Andrew Scharlack, Ph.D., University of California, Berkeley (30 minutes)

4. Report from the Executive Subcommittee

   --LTC Council Work Groups—Updates (20 minutes)
   - Coordinating Community LTC Programs Workgroup
   - LTC Data Workgroup
   - Nursing Home Assessment and Transition Workgroup
   - LTC Consumer Information Workgroup
   - Licensing and Regulation Workgroup

   --Informal Comments on the Council's Activities (5 minutes)

9. General Public Testimony (60 minutes)

10. Closing Remarks (5 minutes)

Chairman

Grantland Johnson
Secretary, Health and Human Services Agency

Council Members

Cliff Allenby
Director, Developmental Services

Diana Bontá
Director, Health Services

Julie Bornstein
Director, Housing and Community Development

Dr. Catherine Campisi
Director, Rehabilitation

Kathryn Jett
Director, Alcohol and Drug Programs

Dr. Stephen Mayberg
Director, Mental Health

Jeff Morales
Director, Transportation

Rita Saenz
Director, Social Services

Lynda Terry,
Director, Aging

Bruce Thiesen
Interim Secretary, Veterans Affairs

Dr. David Carlisle
Director, Office of Statewide Health Planning and Development

You are invited to

The Long Term Care Council Meeting

Sierra Health Foundation

1321 Garden Highway

Sacramento California 95833 (916) 922-4755

October 17, 2001 1:30 – 4:30 p.m.

Chairman

Grantland Johnson
Secretary, Health and Human Services Agency

Council Members

Cliff Allenby
Director, Developmental Services

Diana Bontá
Director, Health Services

Julie Bornstein
Director, Housing and Community Development

Dr. Catherine Campisi
Director, Rehabilitation

Kathryn Jett
Director, Alcohol and Drug Programs

Dr. Stephen Mayberg
Director, Mental Health

Jeff Morales
Director, Transportation

Rita Saenz
Director, Social Services

Lynda Terry,
Director, Aging

Bruce Thiesen
Interim Secretary, Veterans Affairs

Dr. David Carlisle
Director, Office of Statewide Health Planning and Development

Agenda

1. Introductions and Opening Comments—Grantland Johnson, Secretary, CA Health and Human Services (CHHS) Agency (10 minutes)

2. Progress Report from Two Innovation Grants (35 minutes)
   --"Geriatric Medical Psychiatric Inpatient Unit Project"
   Lin Benjamin
   --"Community Outreach for Independent Living"
   Derrell Kelch and Kathy Diagle

3. Supportive Housing Initiative Act (SHIA) Program Update (35 minutes)
   -- Carol Goodman, Department of Mental Health
   -- Kate Hutchinson, Yolo County Community Care Continuum

4. Executive Subcommittee Report (25 minutes)
   - Informal Comments on the Council's Activities
   - Coordinating Community LTC Programs Workgroup
   - LTC Data Workgroup
   - Nursing Home Assessment and Transition Workgroup
   - LTC Consumer Information Workgroup
   - Licensing and Regulation Workgroup
   - AB 499 Workgroup

5. General Public Testimony (60 minutes)
6. Closing Remarks (5 minutes)

Appendix 3--Brief Summary of Olmstead Ruling

Olmstead Decision

In July 1999, as AB 452 was being considered by the California Legislature, the United States Supreme Count rendered a major decision in the case of Olmstead v. L.C. The case involved two sisters confined to a Georgia state mental hospital, who had been assessed as appropriate for community placement, but had not been placed in a reasonable time period.

In the Olmstead case, the Court clarified Title II of the Americans with Disabilities Act (ADA). Title II provides that a person with a disability has a right to services in the most integrated appropriate setting. The Court ruled that an individual receiving mental health services has a right to live in a community setting so long as three conditions were met:

- The person's treating physician determines that community placement is appropriate;
- The individual does not oppose such placement; and
- The placement can be reasonably accommodated, taking into account the resources available to the state and the needs of other that are receiving state-supported disability services.

The Supreme Court, in a concurring opinion, indicated that states could establish compliance with Title II of the ADA if it demonstrates that it has:

- A comprehensive, effective working plan for placing qualified persons with disabilities in less restrictive settings; and
- A waiting list that moves at a reasonable pace not controlled by the State's endeavors to keep its institutions fully populated.

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Appendix 3--Brief Summary of Olmstead Ruling, Continued

Federal Directives	Following the Olmstead ruling, the federal Department of Health and Human Services (DHHS) sent letters to each Governor urging states to create state Olmstead implementation plans. The Health Care Financing Administration (HCFA) and the DHHS Office of Civil Rights (ORC) also sent a joint letter to state Medicaid Directors providing guidance in the creation of such a plan. The Medicaid directors letter indicates that "states are required to provide community-based service for persons with disabilities who would otherwise be entitled to institutional services" under the three conditions stipulated in the Supreme Court ruling.
LTC Council's Role	The Long Term Care Council has been assigned the central role in Olmstead planning and implementation in California. The Council's Mission and Vision Statement includes an Action Statement that explicitly addresses the steps the State plans to take to modify the existing processes to assist individuals who wish to transition into more independent living settings.

Appendix 4--Public Forums—Summary of Key Themes

The key themes that were heard repeatedly at Public Forums have been summarized in this document. It should be noted that these were statements made by consumers, their family members, advocates and other stakeholders. These are personal opinions and comments that have not been verified by the Health and Human Services Agency Long Term Care Council.

KEY THEMES

Family Caregiving/Family Relations

- Family caregiving education is essential. Without it, family members will more easily become frustrated and potentially abusive. Out of ignorance, they may neglect needed care.
- More education needs to be done on advanced directives to ensure that abusive family members don't embezzle an individual's assets.
- Many parents are caring for their adult children who have developmental, psychiatric, traumatic brain injuries or other conditions. They worry about what will happen to their children when they are no longer strong enough to continue taking care of them.

Diversity Outreach

- California is a very diverse state and all of these diverse communities need to be involved in this process both at the state and the local level.
- More ethnic aging/long term care services are needed.

Housing Issues

- The lack of supportive housing for the disabled makes it very difficult for some nursing home residents to transition into independent housing.
- The cost of housing in rural areas has increased significantly. But the housing formulas have not kept pace with these changes in some parts of the state.
- Many low-income individuals live in mobile homes. But those rents have also gone up significantly. If modifications are needed to make a mobile home more accessible or other repairs are required, banks won't make loans to finance those costs.
- In Sierra County, there is no HUD Section 8 housing. None of the churches in the area are wheelchair accessible.
- Housing is essential. If an individual can't find housing, they can't access IHSS.
- The state should take leadership efforts in creating incentives for builders to include "Universal Design" in new structures. So many homes are designed with features that become major barriers to aging in place.
- More HUD housing for the disabled is needed.

In-Home Supportive Services/Personal Care Attendant

- At each session, IHSS workers wages came up. It is very difficult to find and keep good workers. IHSS workers are not reimbursed for their mileage getting to and from their employer and in rural areas this makes it even more difficult to find workers.
- If the current limit on the number of authorized IHSS hours was expanded some nursing home residents could transition out of those facilities. Some do not need medical oversight, they just need 24-hour attendant care.
- The way IHSS hours are determined should be restructured to better meet the needs of individuals who have psychiatric disabilities.
- The current IHSS assessment process does not work for many individuals with Traumatic or Acquired Brain Injuries since their functional and cognitive limitations are not necessarily constant.
- Counseling and mediation training should be made available to IHHS workers who sometimes work with very difficult, manipulative individuals.

Long Term Care Information Access

- People need help in learning what services they are eligible for and what the enrollment process is. Many people have no idea what they are eligible for.
- General Medi-Cal eligibility information should be put on the web.
- Some programs have very helpful consumer information but consumers don't know how to get linked up with those programs.
- It takes too long and is too complicated for family members to get the information they need to help their parents find services. While some providers and agencies can be helpful, they only know about their particular service. Even health care professionals find it difficult to understand what the options are and negotiate arranging for them.
- Consumers and even local agencies don't know about some of the Medi-Cal waiver programs.

Medi-Cal Issues

At two meetings, in discussing the new incentives for the disabled to enter the workforce, consumers stated that the Medi-Cal eligibility rules related to asset accumulation, income allowance amounts, and estate recovery are major disincentives to encouraging individuals to seek employment.

Mental Health Issues

- Many elderly have mental health issues that are not being addressed.
- Some mental health clients require short-term hospitalization from time to time. But in doing so, they become homeless because landlords evict them while they're hospitalized. This makes it even more challenging to find housing and start all over when they leave the hospital.

Innovative Programs

- Rapid Response System within Alameda County Public Authority—If the IHSS worker doesn't show up for some reason, another worker is sent out to assist the individual. On-call workers are maintained to respond to these emergencies.
- In San Diego, an organization called "House Calls" does just that. Doctors make house calls and utilize new, portable technology to do tests at home. This results in a rapid response to a significant change in a patient's health care and avoids unnecessary emergency room visits.
- AARP members in San Diego shared information about a successful Money Management program AARP has piloted in Texas. They noted the need for these types of programs as the population with cognitive limitations increases.

Respite Services

- Family caregivers need respite assistance. One family member who has a child with developmental disabilities noted that they receive 20 hours of respite a month through the regional center. But if she wanted to get away to visit family out of the area or have a real break, she would have to save up several months of this respite in order to do so.
- Families who have a child with communication problems are very reluctant to use institutional respite services. The staff that would be interacting with the child change all the time and would not be able to understand or effectively communicate with her. Parents have requested assistive technology that would help in communications but this has not been forthcoming.

Transportation Issues

At each forum, individuals spoke to the difficulty they had in securing and using public transportation services for routine travel. Individuals who used paratransit noted how difficult it is to have to wait for two hours to be picked up and incidents that have occurred when the van failed to pick them up after it had deposited them somewhere hours earlier.

Workforce Issues

- The difficulty in finding direct care staff came up repeatedly at all meetings from the full range of long-term care providers—home care through nursing home providers.
- Wage and health benefits for workers came up at all sessions.
- If an IHSS recipient goes into the hospital, his/her worker does not get paid. Yet the IHSS recipient will need that worker when he/she gets home from the hospital. One suggestion was that while that person is in the hospital, that IHSS worker could be used on a Rapid Response pool of workers to fill in for individuals who are sick or have other emergencies. In that way, the worker would continue to be paid but would be available again when their employer was discharged from the hospital.

Appendix 5--LTC Council's Mission, Vision, and Guiding Principles

California Health and Human Services Agency
Long Term Care Council

Mission and Vision Statement

Chairman

Grantland Johnson
Secretary, Health and Human Services Agency

Council Members

Cliff Allenby
Director, Developmental Services

Diana Bontá
Director, Health Services

Dr. Catherine Campisi
Director, Rehabilitation

Dr. Stephen Mayberg
Director, Mental Health

Rita Saenz
Director, Social Services

Lynda Terry,
Director, Aging

Bruce Thiesen
Interim Secretary, Veterans Affairs

Dr. David Carlisle
Director, Office of Statewide Health Planning and Development

BACKGROUND

California currently has an array of public long-term care programs. What the State is continuing to develop is a long-term care system out of this set of services that:

- will permit consumers to find the information needed to make informed decisions about their options;
- further promote the development of an array of care options;
- assure meaningful care standards; and
- assure that the options available provide high quality care.

The development of the Long-Term Care Council, as authorized in AB 452 (Chapter 895, Statutes of 1998), is one key step in addressing these issues collaboratively across the State departments administering public long-term care programs.

DEFINING LONG-TERM CARE

Long-term care is a set of social, personal care, health, mental health, substance abuse treatment and protective services required over a sustained time period by a person who has lost or never acquired some degree of physical or cognitive capacity, as measured by a functional and cognitive assessment rather than being tied to a specific diagnosis or linked exclusively to age.

LONG TERM CARE COUNCIL'S MISSION STATEMENT

The Long-Term Care Council will provide state-level leadership in developing a coordinated long-term care system that includes a full array of services, that promotes personal choice and independence while also assuring fiscal responsibility and equitable access to all long-term care consumers.

VISION STATEMENT

A long-term care system that supports consumer dignity and independence, provides a full array of care options and is cost effective.

VALUES STATEMENT

FOCUS ON PREVENTION

Resources are allocated to prevention and wellness activities to minimize disability, prevent secondary disabilities, and promote health, regardless of age or disability. Diet, nutrition education, exercise, oral health, smoking cessation, vaccination programs and early detection/treatment of the diseases that lead to chronic, long-term health conditions can significantly decrease the need for long-term care. Attention must also be focused on preventing the development of secondary disabilities, which often go undiagnosed in persons with disabilities. Consumer education efforts, as well as health care provider resources on these issues, are essential tools to be incorporated in our long-term care strategic planning effort.

RESPECT FOR DIVERSITY

California is a multi-lingual, multi-ethnic society. There is also great diversity among the consumers of long-term care in their abilities and their needs. All these aspects of diversity must be recognized in our planning efforts. An infant born with developmental disabilities, a teenager who is quadriplegic due to a car accident, a young adult experiencing the onset of serious mental illness, an adult with AIDS, and an elder who cannot walk or speak because of a stroke are all consumers of long-term care services. Individuals requiring long-term care assistance have a broad range of functional and/or cognitive abilities.
Information and services must be provided in a manner that meets the cultural, linguistic, and sensory needs of these diverse populations.

HONORING CHOICE, DIGNITY, INDEPENDENCE AND QUALITY OF LIFE

Quality of life is a critical value to be honored. Individuals needing long term care assistance are encouraged to learn about service options and identify their preferences and choices. Services are designed and delivered in a way that fosters the consumer's physical and emotional independence and dignity; allows consumers or their surrogate decision-makers to make informed choices based on the defined risks and benefits of care options; and provides for health and well-being free from neglect and abuse.

SEEKING INPUT FROM CONSUMERS, FAMILY CAREGIVERS, AND THE COMMUNITY

The State will develop opportunities for on-going local and state-level consumer, family caregiver, provider and community input in the design and administration of all publicly funded long-term care programs.

Improving Access to Timely, Complete, and User-Friendly Information and Services

Consumers need better access to timely, comprehensive, understandable information on the full array of long term care options available to aid them in understanding their options. The State, in coordination with local agencies, will place a high priority on developing this type of information in various mediums and languages and it will also collaborate with local agencies to improve coordinated access to services at the local level.

Developing a Full Array of Services

A full array of long-term care service options is needed to assure that consumers can receive assistance in the most integrated setting. Appropriate care empowers people physically and emotionally. The State is taking steps to improve the long-term care system so that Californians needing this assistance can continue to be integrated members of the community in which they live.

Using Assistive and Other Forms of Technology

Technology will continue to be used to empower consumers, reduce the need for traditional services, improve access to consumer information, improve and enhance care delivery, and make better information available to public policy makers.

Expanding the Availability of Palliative Care

Palliative care is a comprehensive team approach to caring for people with life-limiting illness. Palliative care involves caring for the whole person—physically, emotionally, socially, and spiritually. It recognizes that dying is a natural part of life and that the patient's loved ones need support also. The State will strengthen and expand existing partnerships to increase the availability of palliative care and to encourage consumers to talk with their loved ones and health care providers about their end-of-life wishes.

Developing Service Coordination Strategies to Assure that Consumers Receive the Right Services at the Right Time

Assistance with service coordination (often also referred to as "care management") is a valuable tool for many consumers either periodically or on an on-going basis.

This role includes: assessing a consumer's functional and cognitive capacity; determining, with input from the individual or their surrogate decision-makers, the appropriate and available services; arranging for needed services; and assuring the adequacy and quality of the services being provided. This planning should actively

solicit the consumer's preferences and choices in the planning process and include the consumer's satisfaction with the services in the monitoring process.
Strategies to expand the availability of this service in a way that is complementary to consumer-directed care must be developed.

SUPPORTING CAREGIVERS

The State recognizes in its policy development and system building that family and friends provide considerable long-term care assistance. Acknowledging this important contribution, the State will seek additional opportunities, through existing or new programs, to support these caregivers particularly through training and respite opportunities. Practices that promote respect for the dignity and rights of both consumers and providers of long term care are necessary to create an efficient and caring long-term care system.

Long-Term Care Workforce Availability

Health and long-term care providers across the nation are facing workforce shortages that will negatively impact their ability to provide and expand long-term care options. The State will work with these stakeholders to identify successful strategies that encourage individuals to enter, become well trained and remain in a broad range of care giving roles. Attention must also be directed to developing a workforce that reflects the population that is being served and that can provide those services in a consumer-directed culturally competent manner.

ENCOURAGING FLEXIBILITY AND INNOVATION

The State seeks to act as a "promoter" of new long term care models, particularly models that integrate care services to improve client access, care coordination, and service flexibility. As long-term care service delivery systems evolve, the State will continue to learn from various pilot programs and initiatives here and in other states and encourage replication of successful demonstrations of new care delivery/financing models.

NEED FOR IMPROVED PROGRAM INFORMATION TO FACILITATE STRATEGIC PLANNING

Additional information on the characteristics of long-term care consumers being served, the types of services being utilized, caseload trends, and a more comprehensive understanding the distribution of program expenditures is not readily available to service providers or local or state policymakers. To effectively manage these programs and conduct viable strategic planning, such information is needed. The State will provide leadership in developing a plan to improve the type of data available for these purposes.

PROVIDING EDUCATION ON THE RISK OF NEEDING LONG-TERM CARE AND VIABLE OPTIONS AVAILABLE TO PLAN AHEAD FOR THAT POTENTIAL NEED

The State will educate consumers and employers on the risks and costs associated with needing long-term care and will promote and encourage personal responsibility in planning for long-term care needs through the purchase of private insurance and other

financial mechanisms. Encouraging private planning for long-term care will more equitably distribute the burden of providing care between the public and private sectors.

ASSURING RESPONSIBLE STEWARDSHIP

The State will act as a responsible steward by administering a long term care system which:

- Is responsive to and involves the consumers it serves;
- Provides high quality services;
- Is cost effective in purchasing services by obtaining the optimum consumer outcome for the expenditure;
- Is cost effective in operations and administration by maximizing coordination between the numerous state and local agencies involved and reducing duplication of effort;
- Maximizes the use of federal funding in order to expand the full range of long term care options, including assistive, independent, and supported living services;
- Is sustainable over time; and
- Actively collaborates with the private sector, philanthropic organizations, universities, and volunteer groups.

ACTION STATEMENT

The Long Term Care Council, through its Executive Subcommittee, intends to collaborate with all long term care stakeholders, including persons with disabilities, their families and representatives, service providers, counties, and public and private entities to expand cost-effective community supports and services to prevent unnecessary institutionalization.

The Council's action steps will also include modifying, where appropriate, the existing process of assessing individuals currently residing in institutional settings who wish to transition to a more independent living situation. This assessment will identify the individual's existing financial and care support resources and identify any barriers in relocation; explore the development of appropriate resources; assist in the transition process; and provide monitoring during the transition to ensure that the new setting can meet the consumer's health and safety needs. The State is ready to undertake pilot projects to begin this assessment process, which would help shape a larger scale undertaking.

The Council's first action steps will focus on care settings that have been identified as priorities by persons with disabilities, their families, and advocates. A draft assessment tool is being prepared and will soon be ready for review and comment.

In this early stage of its activities, the LTC Council, through the Executive Subcommittee, plans to hold listening sessions throughout the state to meet with LTC stakeholders, particularly individuals with disabilities and their families and representatives who cannot travel to the Capitol, to better understand their concerns and the barriers they encounter in accessing LTC services and to engage them as collaborators in our planning efforts. These comments will be formally recorded. Based on this input, the Council will develop a draft strategic plan; circulate that plan for comment; and formalize the plan.